Patient and Public Involvement in DRN Research Groups

The Diabetes Research Network (DRN) is committed to involving people with diabetes, their carers and family members, in its activities. The remit of the Research Groups, supported by the DRN Clinical Studies Advisory Group, includes the need for patient/public involvement: "*Research Groups must demonstrate that they have input from people with diabetes and carers who have shown an interest in research in the topic covered by the group*".

The DRN believes that effective PPI within the Research Groups will help to broaden the research agenda, and assist in developing study questions and protocols that are more relevant to the public and the target populations from which we wish to recruit.

Early involvement is encouraged. Although first meetings may only consider topics or themes for later discussion, the involvement of patients and carers at this stage may lead to more relevant topics being put on the agenda. It will also ensure that patient and carer members contribute more effectively to later discussions, as they will not be "playing catch up" with those in the Research Group who have attended earlier meetings or discussions.

How can the public help?

Engaged effectively, people can:

- help to identify and prioritise **research topics**
- help to **design** research studies
- help to **develop** patient information materials
- help with the **conduct** of studies, by joining a study Steering Group
- help with **study recruitment**, advising on outreach/recruitment methods.

INVOLVE (formerly 'Consumers in NHS Research') has led the way in engaging and actively involving patients and carers in research. Among INVOLVE's excellent guidelines are two pieces of invaluable advice:

- bring in the **right people** at the right place in the organisation, and
- be **clear from the outset** what you want people to do and what they (and the group) may be able to achieve.

The **right people** aren't those who say what you want them to say, but those who are able to share their knowledge and experience in a positive and meaningful way, and who can listen and contribute in equal measure. And **clarity** is essential – ensure that those invited to join the group know what the group is trying to achieve, and what their role is within the group. A joint group remit and role description could prevent any misunderstandings or unrealistic expectations.

Recruiting patient and public members

The DRN Coordinating Centre, and your DRN Local Research Network, has a list of contact details of people wishing to become actively involved. Many of these have already completed a 'Recruitment Questionnaire', indicating their particular areas of interest (and any specific skills or knowledge that might be appropriate) and may have had some training in the research process from the DRN. The DRN Patient & Public Liaison Officer may be able to offer advice on the recruitment process.

Alternatively, you may know of people in local clinics (or participants from previous studies) who have shown an interest in the research process. Or you can advertise for people to join the group, as you might for a research study (with local permissions, but without the necessity of ethical approval as it is for involvement, not participation in a study).

Many PCTs and NHS Trusts (especially Foundation Trusts) have a patient and public forum of some description. Foundation Trusts offer membership to patients and their families, and some will have more than 100,000 members on their database – and they often have a newsletter which is circulated to all members.

Support for Patient Advocates

Effective support for patient advocates engaged with the Research Groups is essential. In line with the general principles of patient involvement, the following should be the minimum level of support:

- Full reimbursement of all reasonable expenditure – by the quickest and easiest method possible for the patient advocate
- Access to suitable training, both within the DRN and NIHR-CRN, and external courses.
- The availability of a mentor for members of Research Groups where there may be a high level of technical discussion.

Support is also available in the form of two DRN glossaries:

- A *DRN Glossary of Diabetes and Clinical Research*
- A *DRN Glossary of Acronyms and Abbreviations*

GOOD PRACTICE GUIDELINES

The following recommendations are considered good practice for involving people affected by diabetes in research:

- Appoint **three patient advocates** so that they can offer a wider range of views and mutual support. When only two patient advocates are appointed, there is little mutual support when one is unable to attend. And however good individuals may be, one person attending a meeting offers a limited range of views
- Select the **right people** (not those who have the same point of view, but those who are able to communicate their views appropriately)
- Find a reliable method to **reimburse expenses** effectively.

- The views and perspectives of people affected by diabetes should be treated with respect at all times
- The timing and venue of meetings involving people affected by diabetes should take into account their needs and preferences
- The roles of people affected by diabetes should be clearly defined
- Training to support the involvement of people affected by diabetes should be offered
- Mentoring, as a means of technical support, should be offered to people affected by diabetes while preparing for and participating in meetings.

If you would like to discuss how to involve patients and carers in your Research Group, please contact the DRN's Patient & Public Liaison Officer:

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